SOLID ORGAN TRANSPLANT: CHILD LIFE AND IMPACT ON FAMILY

by

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STATEMENT OF THESIS APPROVAL

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ABSTRACT

The goal of the study is to understand the relationship between the impact of illness on the family, sibling functioning, and Child Life Services when a child in the family had received a heart, kidney, or liver transplant at Primary Children's Hospital. Twenty-eight families participated. Parents completed the Impact on Family Scale and Brief Problem Monitor-Parent Form and siblings of transplant recipients completed the Sibling Perception Questionnaire. The surveys were utilized to assess the impact of illness on the family, sibling behavior problems, and siblings' perceptions of how the illness affected family life. A Child Life Services Survey was created for the purposes of this study to assess frequency, satisfaction, and availability of Child Life Services, as well as parents' perceptions of the effectiveness and quality of Child Life Services. Analyses of the quantitative data revealed that families who were more affected by the illness also received more Child Life Services as reported by the mother. The data also revealed that siblings had more attention problems when the transplanted child required more time to manage his or her health care needs. Analyses of the qualitative data indicate that Child Life Services were valued by and meaningful for patients and families; however, the quality of services received appeared to be limited by an insufficient number of Child Life Specialists available to the patients and families. Implications include a need for more Child Life staff, improved sibling services, a need to empower parents, and increased communication regarding the role of Child Life to better meet the needs of patients and families.

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Introduction

Children who are diagnosed with life-limiting, chronic illnesses undergo extensive medical treatments that are physically and emotionally challenging (Annunziato, Jerson, Seidel, & Glenwick, 2012). Family members of these children, including siblings, also face unique challenges as they experience the illness with their brother or sister (Guite, Lobato, Kao, & Plante, 2004). To compound these challenges, treatment of an illness does not always include support for family members, such as is provided by Child Life Services, which offers developmentally appropriate coping and stress management skills to young patients and their family members (Thompson, 2009).

Recent research has examined the impact on siblings of having a brother or sister with a chronic illness. The studies include siblings of children with illnesses such as cancer, cystic fibrosis, diabetes mellitus, and juvenile idiopathic arthritis, with cancer being the most frequently studied illness. A chronic illness that has received very little attention, however, is solid organ transplant. A solid organ includes many of the major organs of the respiratory, urinary, cardiovascular, and digestive systems, more specifically, the lungs, heart, kidneys, liver, and small bowel (McKinley & O'Loughlin, 2008). For the purposes of the present study, siblings of pediatric patients who have received a heart, liver, or kidney transplant—the only organs transplanted at the study

site—will be considered. It has been noted in previous studies that the stressors and experiences of solid organ transplant, such as frequent hospitalizations and medical treatments that take parents' time and energy away from siblings, are similar in many ways to those of other chronic illnesses. However, there are enough differences, such as the time restraint in receiving treatment, the need for daily medical regimens post-transplantation, and the possibility of organ rejection, that solid organ transplant deserves to be studied independently of other chronic illnesses (Annunziato, Jerson, Seidel, & Glenwick, 2012; Stewart et al., 1993).

The present study extended beyond the current research regarding siblings of children with chronic illness and sought to understand the effects of solid-organ transplant on well siblings, as well as mothers' perception of the effectiveness and quality of Child Life Services during the transplant experience. The purpose of this work is to provide insight into how Child Life interventions and the impact of the illness on the family influence sibling functioning of pediatric solid organ transplant patients. Sibling functioning included the siblings' perceptions of the impact of the illness on their personal lives (i.e., the impact on the siblings' interpersonal relationships, the siblings' intrapersonal feelings about the brother or sister's solid organ transplant experience, and the siblings' fear related to this experience) and the siblings' behavior problems (i.e., internalizing, externalizing, and attention behavior problems as reported by the mother). Additionally, the study sought to inform the health care field of mothers' perceptions of Child Life Services throughout the transplant experience. Parents reported on Child Life Services via a Child Life Services Survey created for the purposes of this study. The

survey included closed- and open-ended statements and questions, producing both quantitative and qualitative results.

Family and Well Sibling Factors

Research has demonstrated that a number of variables, including demographic variables, influence family and sibling functioning when there is a child with a chronic illness in the family unit. Williams et al. (2002) used a structural equation model (SEM) to examine the interrelationships among demographic variables and eight psychosocial variables. The demographic variables included age of the sibling, the specific diagnosis of the ill sibling, the treatment group that the participants were placed in, annual family income, education level of the parent, and socio-economic status (SES). The eight psychosocial variables included five sibling factors: knowledge about the illness, mood or affective responses to the illness, attitude toward the illness, self-esteem, and perception of social support received. The remaining three psychosocial variables were the behavior problems of the sibling as reported by the parent, the level of the parents' mood disturbance, and family cohesion and adaptability as reported by a parent.

Results of this study's analyses revealed that as SES increased, parent mood disturbance decreased, which in turn increased family cohesion. Higher levels of family cohesion were related to fewer sibling behavior problems, a more positive attitude from the sibling about the illness, and higher perceived social support from the sibling. Moreover, fewer sibling behavior problems were associated with greater family cohesion, older age of the sibling, greater social support, and greater knowledge of the illness. When the total effects were considered—that is all of the direct effects in addition to any

indirect effects that were statistically significant—SES was the variable with the strongest effect on parents' mood, sibling behavior problems, and family cohesion. Beyond SES, family cohesion had the strongest effect on sibling behavior problems, with high cohesion associated with all other variables except for self-esteem. These findings demonstrate that a variety of factors significantly contribute to the outcome that the illness has on siblings (Williams et al., 2002).

Positive and Negative Effects

In view of findings that reveal factors which contributed to positive outcomes for siblings of children with chronic illness, it is important to note that research in this area also has pointed towards the existence of negative outcomes. In a study conducted by Havermans et al. (2011), the effects of children's cystic fibrosis (CF) on well siblings were analyzed. Responses to questionnaires from siblings of cystic fibrosis patients were compared to those from children with healthy siblings. The comparison demonstrated that siblings of children with CF rated their quality of life higher than siblings of well children. Also revealed, however, was that CF siblings older than the child with CF reported a higher negative impact—meaning the well siblings perceived that having a brother or sister with CF disrupted their life more significantly—than did younger siblings.

Results from a similar study, examining the effects of both childhood cancer and CF on siblings, demonstrated that siblings experienced negative effects as a result of the illness due to feeling physically or emotionally isolated from parents and receiving less attention from the parents than the ill child (Williams et al., 2009). Manifestations of

negative effects included jealousy, anxiety, anger and resentment, negative behaviors, loneliness and depression, academic problems, low self-esteem, and guilt. Of interest is that the same study also noted positive effects, such as a perceived increase in family closeness, the sibling being more sensitive to the ill child and helping with caregiving, and the sibling experiencing positive personal growth and maturation. Waite-Jones and Madill (2008) found similar mixed effects on siblings. Their study on siblings with a brother or sister with juvenile idiopathic arthritis found that, on the one hand, siblings felt the illness was a positive aspect of their life because it led to closeness, while on the other, it was a negative aspect because the illness was not well enough understood, it contributed to less time with peers as compared to children with healthy siblings, and led to feeling different from other families.

As demonstrated by these previous studies, the effects of illness on siblings are neither consistently positive nor negative—both types of effects are commonly cited. An explanation for this is offered by Bouma and Schweitzer (1990), who state that "the specific nature of the chronic childhood illness is an important determinant of its impact on the family" (p. 722). In an effort to address the mixed results in the literature, Sharpe and Rossiter (2002) completed a meta-analysis of 50 studies regarding the effects of having a brother or sister with a chronic illness. According to their analysis, these effects were more negative than positive. These negative effects included increased levels of depression and anxiety, as well as decreased cognitive development scores and fewer activities with peers, as compared to children with healthy siblings.

Discrepancies in the Data

The mixed results of having a brother or a sister who has undergone a solid organ transplant are clouded by methodological issues. Discrepancies between parent reports of siblings and child reports have been noted. This leads to uncertainty regarding the extent of the positive and negative effects of having a brother or sister with a chronic illness because it is unclear which reporters—parents or children themselves—are more revealing of actual effects of having a sibling with an organ transplant. In a study conducted by Guite, Lobato, Kao, and Plante (2004), the effect of chronic illness and disability differed as a function of who was reporting on these effects. Specifically, parent and sibling reports differed when the sibling was a younger male. In this instance, the younger male siblings reported worse adjustment than did the parent. However, the remainder of the sample indicated that the parent was more likely to report more sibling adjustment problems than the sibling did.

Sharpe and Rossiter (2002) reported very similar findings in which the parent tended to characterize siblings more negatively than did the siblings themselves. Unfortunately, with regard to the discrepancy in parent and sibling reports, there is no way of knowing which report is more valid. Sharpe and Rossiter (2002) suggest that validity is unknown due to the observation that siblings may not perceive negative effects until adulthood or they may deny negative effects. Additionally, parents may report more negative effects as a result of their increased stress or they may report more positively than reality in an effort to protect their children (Sharpe & Rossiter, 2002). The authors recommended that an outside observer is needed to understand the true effects of childhood chronic illness on siblings (Sharpe & Rossiter, 2002). Unfortunately, for the

present study, an outside observer was not utilized due to the retrospective nature of the data collection. An outside observer would need to be present at the onset of illness. However, this study only collected data from well siblings of pediatric transplant patients that were posttransplant and did not consider well siblings of patients who had a new onset of organ failure and were on the transplant list at the time of the study. Even so, the data collection for the present study sought to provide valid reports of the effects of having a brother or sister who had received a solid organ transplant.

Support Services and Interventions

Medical and support staff working with families who have a child with a chronic illness can seek to improve family outcomes by providing developmentally appropriate interventions that address the challenges that families face with a child with a chronic illness (Sharpe & Rossiter, 2002; Williams et al., 2009). Child Life professionals are specifically trained to provide such support; however, the impact of their services has not been widely studied for siblings of children with a chronic illness, in general, or specifically with siblings of children who have undergone a solid organ transplant. Studies that are largely non-Child-Life-specific have been conducted to determine the benefits of having support programs in place for family members to utilize. Thus far, interventions such as inpatient family-oriented rehabilitation, community-based family-support programs, and support groups have improved quality of life and perceptions of self-competence, increased knowledge of the illness, decreased behavioral and emotional symptoms, such as hyperactivity, conduct problems, and problems with prosocial

behavior, and provided better overall adjustment for siblings (Besier, Hölling, Schlack, West, & Goldbeck, 2010; Chernoff, Ireys, DeVet, & Young, 2002; Lobato & Kao, 2005).

CURRENT STUDY

Considering the current review of literature, and the solid organ transplant population being largely absent from studies of the effects of childhood illness on siblings, as well as the limited research on Child Life Services, the present study examined the impact on the sibling of having a brother or sister who has undergone a solid organ transplant and parents' perceptions of the effectiveness and quality of Child Life Services. Although it is recognized that the effects of solid organ transplant on a sibling may be the same as or similar to effects experienced within other populations, research on the solid organ transplant population should be treated as a unique and separate population from those previously studied (Stewart et al., 1993). Quantitative survey data were collected from both the mother and a sibling of solid organ transplant patients in order to further understand the effects on siblings and the roles played by Child Life Services and the impact of the illness on the family in this process. Qualitative data regarding Child Life Services were also collected in an effort to understand mothers' perceptions of the Child Life Services they received throughout the transplant experience. Both parents were invited to participate in the study in an effort to increase the response rate to study participation. However, due to the low response rate of fathers, only mothers were included in the final analyses and results.

Hypotheses

Four hypotheses guided the quantitative portion of the proposed study. The first hypothesis was that families who more frequently participated in Child Life Services and had a higher level of satisfaction with these services would have a less severe impact of the illness on the family. This hypothesis was tested using correlations and regression analysis. The independent variables were frequency of participation and satisfaction with Child Life Services. The dependent variable was the impact of the illness on the family.

The second hypothesis was that families who more frequently participated in Child Life Services and had a higher level of satisfaction with these services would have well siblings with increased sibling functioning (i.e., lower internalizing and externalizing behaviors and more positive results regarding the impact of the illness). This hypothesis was tested using correlations and regression analysis. The independent variables were frequency of participation and satisfaction with Child Life Services. The dependent variable was sibling functioning. The analysis was run twice to assess the relationship between Child Life Services and sibling functioning as reported by the sibling (Sibling Perception Questionnaire) and Child Life Services and sibling functioning as reported by the parent (Brief Problem Monitor-Parent Form).

The third hypothesis was that families with a less negative impact of the illness on the family and increased participation in and higher satisfaction with Child Life Services would have well siblings with increased sibling functioning. The hypothesis was analyzed using correlations and regression analysis. The independent variables were the impact of the illness on the family and frequency of participation in and satisfaction with

Child Life Services. The dependent variable was sibling functioning. The analysis was run twice as done with the previous hypothesis.

The fourth hypothesis was that families who had a child that required less transplant care as indicated by the amount of time required to care for the child's health care needs posttransplant, by the mother or by the transplant recipient, would have a lower impact of the illness on the family and better sibling functioning. The hypothesis was analyzed using correlation and regression analysis. The independent variable was transplant care. The dependent variables were impact of the illness on the family and sibling functioning.

METHOD

Design

This was a mixed methods study aimed at understanding the relationship between frequency, satisfaction, and availability of Child Life Services, impact of the illness on the family, and sibling functioning, as well as mothers' perceptions of the effectiveness and quality of the Child Life Services received by the ill child, sibling, and parents during their transplant experience. The purpose of the study was to better understand the impact of solid organ transplant on siblings and the role of Child Life in the patients' and families' health care experience. Quantitative data were gathered to assess the relationship between the impact of the illness on the family, sibling functioning, and Child Life Services. Qualitative data were gathered to assess mothers' perceptions of the effectiveness and quality of Child Life Services.

Participants

Potential participants were identified through medical records available at Primary Children's Hospital (PCH). The University of Utah hospital was also included in data collection as outpatient clinic services for pediatric kidney transplant patients are provided at University hospital, while pediatric heart and liver outpatient clinic services

are provided at PCH. All inpatient services are provided at PCH. Families who had a child that experienced a solid organ transplant between 2007 and 2013 were invited to participate in the study. In order to participate, the family had to have a sibling between the age of 6 and 18 and they had to be able to complete the surveys in English. Due to the low number of families speaking a primary language other than English, translation of the study materials was not considered. In total, an attempt to make initial contact was made with 155 families. From the initial contact, 48 families that were eligible to participate agreed to participate and were sent a survey packet. Of the 48 packets that were sent, 28 packets were returned. Thus, the overall response rate for the present study, based on attempt to contact, was 21%. Of those who participated, the sibling that participated in data collection, if there was more than one sibling in the family unit, was the sibling who was between the ages of 6 and 18 and was closest in age to the child with the solid organ transplant, which is consistent with previous research (Havermans et al., 2011; Kao, Plante, & Lobato, 2009). Parents also participated in data collection.

Procedures

All potential participants were mailed an invitation to participate in the proposed study. A follow-up phone call was made to identify which potential participants would like to participate and qualified for participation. Consent to participate in the study was provided by the parent or parents. Assent was given by the sibling who participated, unless he or she was 18 years of age, in which case the sibling also provided consent. After all participants were identified, questionnaires were mailed to the participants' homes. The parent or parents completed questionnaires regarding perception of the

impact of the illness on family life, participation in, satisfaction with, and types of Child Life Services received, as well as the effectiveness and quality of Child Life Services, internalizing and externalizing behaviors of the well sibling, information regarding the transplant, and demographic information. Well siblings completed a survey regarding their perceptions of the impact that their brother or sister's illness has on their life.

Measures

Demographic data. The mothers completed a questionnaire to provide demographic information. Demographic data included family income, family's place of residence (to determine distance to and from the hospital), age of the sibling, whether the sibling is older or younger than the child with the solid organ transplant, race, religious affiliation, parents' highest level of education, and parents' marital status. The demographic variables were used to analyze whether any of these factors influenced or predicted the impact of the illness on the family or sibling functioning. If any demographic variables provided statistically significant predictions, they would have been controlled for in future analyses of the data.

Child Life Services. A survey about the frequency of participation in Child Life Services by the ill child, as well as the well sibling, satisfaction with services, and the types of services received during the transplant process were provided by the parent or parents. The survey inquired about interventions and family support services provided by Child Life Specialists during inpatient stays and outpatient clinic visits, and well siblings' participation in occasional sibling programming (SIBS Day) made available at the hospital.

If the ill child or well sibling did not participate in Child Life Services, the mothers were asked to indicate whether services were offered and refused due to personal preference; not utilized due to schedule conflicts, or physical distance from the hospital; or were unavailable. The purpose of requesting information about Child Life Services was to allow for consideration of the extent to which Child Life interventions affected the impact of the illness on the family and sibling functioning.

The survey included both open- and closed-ended questions. The open-ended questions provided the qualitative data necessary to understand parents' perceptions of the effectiveness and quality of Child Life Services. Parents' reported on what was helpful, what was not helpful, what they felt was important, and what they felt needed to be improved in relation to their experience with Child Life Services for both outpatient appointments and inpatient admissions. For example, parents' responded to the statements "Please explain what aspects of the Child Life Services were helpful during **outpatient** visits," "Please explain what aspects of Child Life Services were NOT helpful during **outpatient** visits," and "Please write anything else you feel is important about your experience with Child Life Services during your **outpatient** visits." Parents also responded to the question, "What do you think could be done differently to improve Child Life Services for you/your child/the sibling during **outpatient** stays?" The previous statements and question were repeated for inpatient admissions. Parents' then reported on the Child Life Services they felt were most helpful and least helpful for the ill child, the well siblings', and for them as the parent. For example, "Overall, what Child Life Services or experiences were **most** helpful for **your child** throughout the transplant experience?" and "Overall, what Child Life Services or experiences were **least** helpful to

you, as the **parent**, throughout the transplant experience?" Lastly, parents reported on their experience with SIBS day. In total, parents' responded to 18 questions about their experience with Child Life Services.

The closed-ended questions on the Child Life survey provided the quantitative data necessary to understand the relationship between Child Life Services, the impact of the illness on the family, and sibling functioning. Parents were first asked to respond to the question "Are you familiar with the Child Life Services available at PCH and University Hospital?" If yes, parents' were asked to proceed with the remainder of the questions. These questions asked parents about the frequency of the Child Life Services they received, their satisfaction with those services, and their satisfaction with the availability of the services received for both outpatient appointments and inpatient admissions. For example, "How often do you feel that you and your family received Child Life Services during your visits at PCH or University Hospital for **outpatient** visits?" and " How satisfied are you with the availability of Child Life Services during **inpatient** stays?" Response options were 1=Never/Very Unhappy/Very Dissatisfied to 5=Always/Very Happy/Very Satisfied. Parents also responded to a statement about the types of services received during outpatient appointments and inpatient admissions. For example "Please select the kind of services you/your child/the sibling received from Child Life during **inpatient** stays." Parents selected from a list of services that are commonly offered by Child Life. Parents also had the option of filling in an "other" option. Additionally, parents' responded to their overall satisfaction with Child Life Services and whether the sibling participated in SIBS day. In total, parents responded to up to 16 closed questions (Appendix B).

Transplant care. Mothers also completed a short survey regarding the transplant experience for the child who received a solid organ transplant. Questions regarding the specific organ transplanted, when the transplant occurred, how much time it takes the child and the parent to manage the child's health care needs, and if the child resists taking antirejection medications were asked. This was done in an effort to understand how the transplant affected daily family functioning in relation to the other variables (Appendix A).

Impact of illness on the family. Mothers completed the Impact on Family Scale (IOF). The IOF assesses the parent's perception of the impact of the child's illness on family life. Items on the IOF are rated on a 1 to 4 point scale. Higher scores indicate a more negative impact of the child's condition on family life (Stein & Jessop, 1985; Stein & Jessop, 2003). The IOF originally comprised 24 items and 4 subscales. However, its authors conducted psychometric data on the original scale with a higher number of samples than originally used and revised the scale based on their analysis. Thus, the IOF currently has 15 items that compose a composite Total IOF score (Stein & Jessop, 2003). Sample items from the IOF are "Fatigue is a problem for me because of my child's illness," "It is hard to find a reliable person to take care of my child," and "Traveling to the hospital is a strain on me."

Sibling outcomes. Mothers completed the Brief Problem Monitor-Parent Form (BPM-P)—a shortened version of the Child Behavior Checklist (CBCL)—for the sibling that is participating in the study. The CBCL has been used repeatedly in studies of siblings who have a brother or sister with a chronic illness or disability and has been deemed reliable and valid across studies (Kao, Plante, & Lobato, 2009). The BPM-P has

19 items that are rated on a scale of 0 (not true) to 2 (very true) and assess internalizing, externalizing, and attention problems in children. Sample items for internalizing behaviors are, "Feels worthless or inferior," "Too fearful or anxious," and "Unhappy, sad, or depressed." Sample items for externalizing behaviors are "Argues a lot," "Destroys things belonging to his/her family or others," and "Threatens people." Sample items for attention problems are, "Can't sit still, restless, or hyperactive," and "inattentive or easily distracted" (Achenbach, 2011).

Siblings completed the revised Sibling Perception Questionnaire (SPQ), which has been used in several studies to assess siblings' perceptions of their brother' or sister's illness (Guite, Lobato, Kao, & Plante, 2004; Havermans et al., 2011). The SPQ was originally designed to assess school-age siblings' responses to childhood cancer (Sahler & Carpenter, 1989). It has since been revised by Lobato and Kao (2002) due to low individual subscale reliabilities in the original measure. The revised SPQ is an 18-item measure with three subscales—interpersonal, intrapersonal, and fear. The three combined subscales create a composite Negative Adjustment scale in which a higher score indicates a more negative sibling adjustment. Each of the subscales has items that are rated on a scale of 1 (never) to 4 (often). Sample items for each subscale in the SPQ are "I wish my parents would spend less time with my brother/sister," "People care about how I feel," and "My brother or sister's illness affects what we can do as a family" (Interpersonal); "I feel sad about my brother's/sister's illness," "I think about my brother's/sister's illness," and "I understand why my parents have to spend time with my brother/sister," (Intrapersonal); and "I worry that I can catch my brother's/sister's illness" (fear) (Lobato & Kao, 2002).

RESULTS

The proposed study examined the relationships between demographic variables, parents' and siblings' experience with Child Life Services, and the impact of the illness on the family and sibling functioning. All variables were analyzed to identify correlations between the variables. Regression analyses were completed when appropriate. The demographic variables were analyzed with all other variables to determine whether any of the demographic variables had statistically significant relationships with experience with Child Life Services, the impact of the illness on the family, and sibling functioning. The qualitative portion of the Child Life Services survey was analyzed using constant comparison analysis, using the first two stages of the three-stage coding method to create categories and themes that represent the ideas presented by the mothers about their perceptions of the Child Life Services they received.

Quantitative Results

There were two phases to the data analysis plan. First, quantitative analysis was employed to test the study's hypotheses. Second, qualitative analysis was used to address the study's open-ended research questions concerning the effectiveness and quality of Child Life Services.

As a first step in the quantitative analysis, demographic data were analyzed with all variables to identify any potential confounding factors. Demographic variables

included income, race, religion, marital status, parents' education, distance from the hospital, age of the sibling, and whether the sibling was older or younger than the transplanted child. The demographic variables did not significantly correlate with any other variables and thus were not used as controls when testing the hypotheses.

The first hypothesis that increased frequency and satisfaction with Child Life Services would have a less negative impact of the illness on the family was not supported. A correlation between mothers' report of the frequency of inpatient Child Life Services received and the mothers' report of impact of the illness on the family was statistically significant with r (23) = .477* and p = .021 (Table 1). However, no statistically significant correlations were found between satisfaction with Child Life Services and impact of the illness on the family. A regression was conducted to further understand the relationship between mothers' report of Child Life Services and mothers' report of impact of the illness on the family. Impact of the illness on the family as reported by the mother was the dependent variable and mothers' report of the following Child Life Services were the independent variables: frequency of inpatient services, satisfaction of inpatient Child Life Services, satisfaction of availability of Child Life Services, and the number of services received (i.e., the number of specific services [e.g. medical play, procedural support, sibling support, etc.] that the mother reported to have received during inpatient admissions). The regression as a whole was statistically significant with F (4, 18) = 3.822, p = .020. Looking at the individual independent measures, only Child Life frequency and Child Life satisfaction accounted for significant portions of the variance in the Impact on Family scale (Table 2).

Table 1.
Correlations between IOF and Child Life frequency and satisfaction during inpatient admissions

	Impact on Family
Child Life Frequency (*n*=23)	.477*
Child Life Satisfaction (*n*=23)	.080

IOF, Impact on Family Scale; Child Life Frequency and Satisfaction, Child Life Services Survey
**P<0.05*

Table 2.
Regression for IOF and Child Life frequency, satisfaction, satisfaction with availability, and number of services received

	B	**Std. Error β**	**Beta**
(Constant)	*54.218**	14.374	
CL Frequency	6.152*	2.384	.769*
CL Satisfaction	-9.841*	3.907	-.670*
CL Availability	-.034	2.295	-.003
Number of Services	1.524	1.113	.323

IOF, Impact on Family Scale; Child Life frequency, satisfaction, availability, and number of services, Child Life Services Survey
R^2=.459, P<.05

The second hypothesis that families who had increased frequency and satisfaction with Child Life Services would have siblings with increased sibling functioning was not supported. Correlations were examined to identify the relationship between frequency and satisfaction with Child Life Services and siblings' report of sibling functioning as indicated via the Sibling Perception Questionnaire. No statistically significant relationships were found between Child Life Services and each component of the Sibling Perception Questionnaire, namely interpersonal, intrapersonal, fear, and the total or Negative Composite score. Correlations were also examined to assess the relationship between Child Life Services and mothers' report of sibling functioning as reported via the Brief Problem Monitor-Parent Form. Again, no statistically significant relationships were found between Child Life Services and each component of the Brief Problem Monitor-Parent Form, which is internalizing, externalizing, attention problems, and the total BPM-P score (Table 3).

Table 3.
Correlations between Child Life frequency and satisfaction during inpatient admissions and SPQ and BPM-P

	Child Life Frequency	**Child Life Satisfaction**
SPQ (*n*=24)		
Intrapersonal	.118	.000
Interpersonal	.294	.035
Fear	-.129	-210
Total	-.102	-277
BMP-P (*n*=25)		
Internalizing	-*.003*	-050
Externalizing	.012	.098
Attention	-.289	-.252
Total	-.113	-.088

CL Frequency and CL Satisfaction, Child Life Services Survey; SPQ, Sibling Perception Questionnaire; BPM-P, Brief Problem Monitor-Parent Form

The third hypothesis that families with a less negative impact of the illness on the family and increased participation in and higher satisfaction with Child Life Services would have well siblings with increased sibling functioning was also not supported. Correlations for the individual relationships between Child Life Services and the impact of the illness on the family and sibling functioning were conducted for the previous hypothesis (see Table 1, Table 2, and Table 3). Thus, noting the lack of support for the previous hypothesis, further analysis was not considered for the present hypothesis.

The fourth hypothesis that families who have a child that requires less transplant care as evaluated by the time required to care for the ill child by the mother or by the ill child posttransplant would have a lower impact of the illness on the family and better sibling functioning was supported for one aspect of sibling functioning—mothers' report of siblings' attention problems. No statistically significant relationships were found for time required for posttransplant care and the impact of the illness on the family. Additionally, no statistically significant relationships were found between time required for posttransplant care and any component of the Sibling Perception Questionnaire or the internalizing, externalizing, or total components of the Brief Problem Monitor-Parent Form. However, the amount of time the mother reported that she spent caring for the child that received the transplant was positively correlated with mothers' report of siblings' attention problems with r (26) = .495* and p = .010. Additionally, the amount of time the mother reported that the ill child spent caring for him or herself was positively correlated with mothers' report of siblings' attention problems with r (26) = .464* and p = .017 (Table 4). A regression analysis was conducted to identify whether time spent caring for the child by the mother or whether time spent caring for the child by the child

was a greater predictor of siblings' attention problems. The regression as a whole was statistically significant with F (2, 23) = 4.803, p = .018; however, the independent variables of time caring for the child by mother or by child were not statistically significant (Table 5). It is possible that siblings who have an ill brother or sister that requires more time to manage health care needs are concerned with the well-being of their brother or sister, and are thus distracted with this concern and unable to focus on activities for an appropriate amount of time.

Table 4.
Correlations between time spent managing health care needs by mother and by child and BPM-P

	Time by Mother	Time by Child
BPM-P (*n*=26)		
Internalizing	.115	.129
Externalizing	.069	.122
Attention	.495*	.464*
Total	.279	.294

Time by Mother and Time by Child, Transplant Care Questionnaire; BPM-P, Brief Problem Monitor-Parent Form
**P<.05*

Table 5.
Regression for siblings' attention problems and time to manage ill child's health care needs by ill child and by mother

	β	Std. Error β	Beta
(Constant)	*1.3**	.573	
Time by Child	.003	.002	.271
Time by Mom	.008	.005	.341

Siblings Attention Problems, Brief Problem Monitor-Parent Form; Time by Child and Time by Mom, Transplant Care Questionnaire
R^2=.295, P<.05

Qualitative Results

Qualitative analysis was employed to learn about parents' perceptions of the effectiveness and quality of Child Life Services. The method used for analyzing the qualitative data was constant comparison analysis. This method, as described by Leech and Onwuegbuzie (2008), is "systematically reducing data to codes, then developing themes from the codes" (p. 601). The development of codes and themes was done in two stages. The first stage was open-coding, where the researcher placed the data into groups and selected a descriptive word, or code, for each group. The second stage was axial coding. In this stage, the researcher took the established codes and grouped them again into similar categories (Leech & Onwuegbuzie, 2008).

For the first stage of the constant comparison analysis employed for the present study, all responses submitted by mothers were coded and categorized by theme on the basis of the main ideas presented. The researcher identified themes by carefully considering the responses to the open-ended statements and questions presented in the Child Life Services survey. As ideas were identified, themes began to emerge based on the frequency of the idea presented and its relevance to the goal of understanding mothers' perceptions of the effectiveness and quality of Child Life Services. A total of 12 individual themes were identified, which were later categorized further into three overriding themes. The three overriding themes were consistency with and availability of services, services that promote coping, and suitability of services. The 12 individual themes were: predictability of services, introduction of services, a need for more Child Life, emotional support, medical play, parent support, procedural preparation, procedural support, sibling support, nonmedical/regular play, age appropriate activities, and accurate

assessment of and subsequent interventions for individual patient and family needs (Figure 1). Each will be considered in turn.

The first category of **consistency with and availability of services** included the themes of predictability of services, introduction of services, and a need for more Child Life. This category was created by recognizing that each of the three themes correlated in the sense that they point to the need for Child Life to be reliable. More specifically, patients and families need to be able to rely on Child Life to provide services when needed, to have a consistent Child Life Specialist to work with, and to be more aware of the kinds of services that can be provided by Child Life.

Predictability of services focused on the ideas that Child Life Services were not always available when needed and when they were available, the family wanted consistency in who provided the services. For example, when asked what aspects of Child Life were not helpful, one mother reported, "Not always being there—I didn't know if I could plan on it or not." Another mother responded that "Having one or two main Child Life Specialists we know well and can work with fits us better than working with a new specialist every day or every visit." Thus, the mothers suggested that the patient and family need to be able to predict which Child Life Specialist will be available and when.

The theme of **introduction of services** was identified by comments that suggested parents would like more information regarding the kinds of services Child Life has to offer. For example, one mother stated that while the patient and parents are often asked by Child Life Specialists whether anything is needed, the Child Life Specialists did

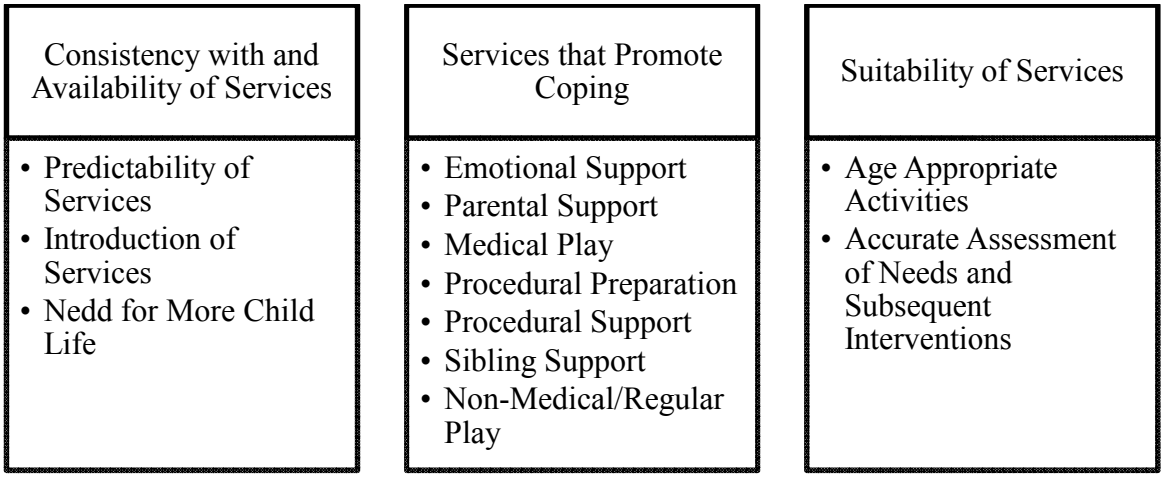

Figure 1. Categories and Themes for Mother's Perceptions of Child Life Services.

not provide information about the specific services that were available, and indicated that "it would be nice to know specifically [how] they could help me with my child."

A need for more Child Life was evident in responses indicating that more Child Life Specialists are needed to meet the needs of each patient and family. Examples include statements such as, "Only one Child Life person for all the children in clinic or on dialysis. They are spread too thin to help as much as the children (patient and siblings) need," "We missed the playtime with Child Life on weekends when they weren't at work," and "Too few Child Life Specialists to help each child and family with each procedure. We really missed them when they were gone or not available. None on swing shifts. Less on weekends."

The second category, **services that promote coping**, included the following seven themes: emotional support, medical play, parent support, procedural preparation, procedural support, sibling support, and nonmedical/regular play. Coping, as cited in Thompson (2009) and defined by Lazarus and Folkman, is "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or

exceeding the resources of the person" (p. 31). The seven themes that fit into the category of services that promote coping are all interventions that Child Life Specialists are trained to provide as part of their role in supporting the well-being of the patient and family. Thus, as Child Life Specialists provided interventions within the presented themes, they were encouraging efforts to manage the demands of chronic illness with transplant and hospitalization, and in turn provided opportunities for healthy coping to occur.

The theme of **emotional support** pointed to mothers' appreciation for the Child Life Specialist's ability to decrease stress and attend to their children's emotional well-being. For example, one mother stated that the "[Child Life Specialist] was a great resource to us. Someone who was a step removed from the medical aspect and more a support for us emotionally." Another mother stated that the "[Child Life Specialist] taking over the situation so we didn't feel so stressed" was helpful.

The themes of medical play, procedural preparation, and procedural support are closely related due to the nature of the interventions. **Medical play** was identified as an important aspect of Child Life Services by mothers who made statements such as, "I feel like medical play of his surgery was very helpful," "Medical play [was helpful], so they learned about their tubes and dressing changes before done on themselves," and "medical dolls help each of my kids deal with stress." **Procedural preparation** was identified by statements such as, a "Child Life Specialist explained to my 11-year-old what a heart transplant entails and played a computer simulation where my child 'performed' an online heart transplant during our initial transplant consultation. This allowed my child to understand transplant on her level and not have to sit in on more

advanced, adult oriented discussions" and "preparation and explaining her surgeries [was helpful]." **Procedural support** contained statements such as, "making our child feel comfortable and distracted during procedures [was helpful]," "being with her while going to the O.R. [operating room]…when we couldn't be there [was helpful], and a "happy, friendly face full of smiles to help the timid child with a procedure [was helpful]." Thus, interventions surrounding the understanding of support during procedures, as well as health care and hospitalization as a whole were noted as being an important aspect of the Child Life Services that the patients' and families received.

The theme of **parent support** as an important aspect of Child Life Services was noted in a manner that suggests the support provided to the children ended up being a support to parents in a variety of ways. For example, one mother noted that scheduled play time with the Child Life Specialist was an intervention that the patient "LOVED" and gave the mother the opportunity to take a break and get breakfast with the patient's father. Another mother commented on how medical play was important for her learning, as well as her children's, stating that "Medical play with [the] kids helped me to learn other ways to talk with my kids about the procedures." Additionally, one mother commented on how Child Life Services for her daughter was emotionally supportive for her as the parent, commenting that, "Helping my daughter know how to cope better relieved some of my stress." In each statement, mothers commented on how an intervention for their child was also supportive for them.

As learning about siblings was a target of this study, **sibling support** was a meaningful theme presented in the qualitative data. The comments made by mothers indicated that when sibling support was provided, it was a helpful service; however,

mothers' comments also suggested the need for improvements regarding sibling support at both the Child Life Services level as well as at the hospital system level. Comments that indicated the importance of sibling services as a means for promoting coping included the idea that play at the hospital was important for the sibling. For example, "the playroom and arts and crafts were a great place to spend time with my healthy children when they came to visit their sister in the hospital." Mothers also mentioned that it was helpful for the siblings to be prepared for what they would experience in the hospital and to learn about the procedures that the transplanted child received. Comments that expressed this idea are, "[The Child Life Specialist] also spent time with our son's siblings, teaching them what to expect when they saw their brother," and "They helped her understand the procedure he was going to get and included her in everything he did." Thus, the sibling services that were provided were noted to be important for helping the siblings cope with their experience.

Comments that suggested a need for improvement in providing sibling services included ideas that pointed to system-level barriers to sibling support, such as, "Honestly, hospital regulations are too stringent right now on visits that the entire experience is one in which my patient's sibling was mostly left out of the entire experience. I think Child Life may have been helpful for the sibling, but he wasn't allowed in the hospital." Comments from mothers also pointed to a Child Life Services level of support that needs to be addressed. For example, "I think trying to include siblings—at least those within a certain age range—would be beneficial. In retrospect, my transplanted child's closest sibling needed to be more involved and could have used classes or a special day where Child Life could have helped him deal with this experience." Additionally, one mother

stated, “Sibling—send a small craft kit/activity—something home that’s fun for them when the sick child leaves. The others feel so very left out, overwhelmed, and often unloved and resent the attention and gifts the sick one gets.” Each of these comments pointed to the idea that at the hospital system-level, siblings may be restricted from being present at the hospital; however, at the Child Life Services level, it is important to mothers that sibling services are offered and provided even if done via the parents because the siblings cannot be present.

Nonmedical/regular play was frequently mentioned in responses as an important aspect of Child Life Services. Mothers often commented on the importance of arts, crafts, and toys being provided for their child to do while at the hospital, as well as the importance of play time with the Child Life Specialist. One mother stated that, “My daughter loved just having someone different from her mother come in the room and talk and play with her. She loved…being left with art supplies to play with.” Other mothers made statements pointing to the importance of nonmedical/regular play for the hospitalized child. For example, one mother mentioned the weekly game of Hospital Bingo that is hosted in the playroom and broadcasted to the patient’s rooms on the hospital channel, stating that, “Hospital bingo [was helpful]—except when she was having procedures, she always played, no matter how sick she got. I just love seeing my kids smile. Toys, crafts, friendly staff and volunteers help her to do that.” Another mother commented that “Being able to play helps her to feel normal again.” Non-medical/regular play was identified as an important aspect of Child Life Services as perceived by the mother.

The third category of **suitability of services** was identified by the recognition that the themes of age appropriate activities and accurate assessment of and subsequent interventions target the same idea. That is, families need to know that they will be able to receive services that meet their needs. Patients and families needed activities that were appropriate for their age and were a good fit for their circumstances. Additionally, Child Life Specialists, while trained on how to assess a family's needs, may have needed to hone in on this skill to ensure that each patient and family was receiving what was best for them.

The theme of **age appropriate activities** pointed to the idea that many activities that were available were meant to support younger children, leaving out the older school-age and adolescent patients and siblings. Examples of this idea included, "He is an older sibling, most things were very childish and for younger siblings," and "Age appropriate things. She is 11 and a lot of the crafts/activities were geared for much younger."

Accurate assessment of and subsequent interventions for individual patient and family needs was identified by ideas that suggested that the support provided by the Child Life Specialist was not always felt by the parent to be needed or helpful. One mother suggested that in certain situations, Child Life was not needed, commenting that "There is usually a Child Life Specialist when he gets labs drawn trying to distract him. I'm not sure he likes this because he's shy around strangers and labs aren't that difficult for him." A second mother stated that she felt that procedural preparation was not helpful for her child that received the transplant because "she was only 4 years old," procedural preparation was not helpful for her as the mother because, "I was so nervous to even listen," and it was not helpful for the siblings because "they just weren't interested."

Another mother also suggested that the support provided was not helpful. In this case, the mother indicated that more should have been done by commenting that

> Personally, I am not one to ask for help or to really voice concerns so when I do it, it is showing that I am wanting some support or ideas. In the past, I have voiced my concerns with my child and all the help I got was it sounds like you have it under control. So I haven't voiced problems since because when I wanted some help I didn't get it. I really just wanted ideas that would maybe help more than what I was doing in regards to my daughter's fluid intake.

Each of these examples point to the need for the Child Life Specialist to be skilled in assessing what kinds of services will be supportive for each patient and family and to be aware of the times when a patient or family is in need of more support and to provide increased support.

The categories of consistency with and availability of services, services that promote coping, and suitability of services and their corresponding themes identify ways that Child Life Services can and do provide support for families. They also identify ways that Child Life can be improved in order to better meet the needs of the patients and families. Hence, each category and its corresponding themes identify mothers' perceptions of the effectiveness and quality of the Child Life Services received throughout the transplant process.

DISCUSSION

The purpose of this study was to examine the relationship between the impact on family, sibling functioning, and Child Life Services in families that have a child that has received a heart, kidney, or liver transplant. Additionally, this study sought to understand mothers' perceptions of Child Life Services at Primary Children's Hospital throughout the transplant experience. In general, the findings indicate a correlation between high impact of the illness on the family and high frequency of Child Life Services, no relationship between impact of the illness on the family and sibling functioning, or Child Life Services and sibling functioning, and a positive correlation between time for transplant care and siblings' attention problems.

The positive relationship between frequency of Child Life Services and the impact of the illness on the family as reported by the mother was unexpected. It was anticipated that families would have a lower impact of the illness on the family when they received more Child Life Services, as a primary goal of Child Life Services is to decrease stress and promote coping. Thus, it seemed appropriate for frequent Child Life Services to be associated with a lower impact of the illness on the family. However, the current research did not assess the impact of the illness on the family prior to transplant. Consequently, it is not possible to assess whether the impact of the illness on the family decreased over time in relation to frequency of Child Life Services. Further research will

need to be done to identify the true relationship that exists. However, one possible explanation for the relationship is that due to the high Child-Life-Specialist-to-patient ratio, the Child Life Specialists prioritized patients and their families based on those that needed services the most. Thus, the higher impact of the illness on the family is reflective of the Child Life Specialists' accurate assessment of and interventions for the families that needed Child Life Services the most.

The lack of findings for sibling functioning was also unexpected. It was anticipated that a lower impact of the illness on the family would be associated with more positive outcomes for siblings. This assumption is based on the idea that when the family is impacted less, the family as a whole is likely to experience less stress overall. As a result, the siblings would have more positive outcomes. It is possible that the lack of relationship between the impact of the illness on the family and sibling functioning supports previous research in which parents' reports of sibling outcomes are not consistent with siblings' report of sibling outcomes. Additionally, due to the nature of the questionnaires utilized for the present study, it was not possible to evaluate the extent to which mothers' reports of siblings and siblings' reports of siblings were aligned. However, correlations were conducted to examine whether a relationship existed. No statistically significant relationships were identified between mothers' and siblings' reports of sibling functioning.

It was also anticipated that a relationship between sibling functioning and frequency and satisfaction with Child Life Services would be found. This anticipation was expected under the previously mentioned objective of Child Life Services to decrease stress and increase healthy coping. Therefore, it seemed appropriate to expect

that the more Child Life Services families received and the more satisfied they were with those services, the fewer problems siblings would have. Based on the information gathered from the qualitative portion of the Child Life Services Survey, it seems that a large portion of siblings did not receive adequate sibling services, if any at all. Thus, further research with siblings who have participated in adequate Child Life sibling services would be beneficial in order to assess the relationship between Child Life Services and sibling functioning.

The positive correlations between the amount of time required to manage health care needs posttransplant and sibling functioning suggest that the time needed to maintain health care regimens is related to siblings' attention problems. This finding is consistent with the literature that indicates that solid organ transplant functions differently than other life-limiting and chronic illnesses, such as cancer, due to the lack of cure present with transplant. Following the transplant, patients are required to maintain a regimen of antirejection medication in order to support the health of the new organ in their bodies. Thus, once a transplant occurs, the patient is not cured as cancer patients often are when they go into remission. The transplant patient, along with cystic fibrosis, diabetes mellitus, and juvenile idiopathic arthritis patients, among others, will have long-term health care needs, whereas other diagnoses may not once treatment has been completed. As a result, a level of uncertainty about the ongoing health of a child that has received a transplant will occur. Due to the uncertainty, it seems likely that siblings will have attention problems as a result of being concerned about the long-term implications of the transplant—especially when the ill child requires more time to manage their health posttransplant. Time, in this instance, is likely to be correlated with health and wellness.

Hence, the more time the child needs to maintain their health, the less healthy they are, and the more concerned and less focused the siblings are. Other possible explanations for this finding include the child receiving less effective parenting due to the parent being stressed as a result of the illness and the siblings perceiving less time with their parents as a result of the parent needing to spend more time with the transplanted child, leading to attention problems in the sibling.

The findings from the qualitative analysis suggest that the role of Child Life Specialists in providing services for patients and families during the transplant experience is important to and valued by those families. However, the qualitative data also suggest that improvements need to be made to better meet the needs of patients and families. The expressed need for Child Life Services as an important aspect of patients' and families' health care experience, as well as the indication that improvements need to be made to better meet patient and family needs, are meaningful for the field of Child Life in advocating for the expansion of Child Life Services in pediatric settings. The satisfaction conveyed by mothers indicates a need for Child Life Services in general. As a whole, mothers reported that Child Life Services were a vital part of the ill child's, sibling's, and parent's health care experience. However, the expression of dissatisfaction did also occur. To address the dissatisfaction conveyed by mothers, it is suggested that increasing the number of Child Life Specialists and improving the patient to Child Life Specialist ratio is an ideal solution. The Child Life Council indicates that the ideal Child Life Specialist to patient ratio is 1 to 15 (Wilson, Palm, & Skinner, 2006). Presently at PCH, the Child Life Specialist to patient ratio is approximately double the ideal ratio at approximately 1 to 30. Considering that improving staffing may take a considerable

amount of time and may not be immediately feasible, other options for addressing the dissatisfaction also are worth considering.

Within the category of consistency with and availability of services, mothers expressed a need to know when services would be provided and by whom, as well as what specific services were available. As stated, an increase in Child Life Specialists would be ideal as a means for addressing these needs. An increase would likely result in Child Life Specialists being able to be present more consistently to meet patients' needs, to better "follow" patients with whom they have worked, and to more clearly explain the services that can be provided by Child Life. However, considering the limitations, it is suggested that Child Life Specialists consider empowering parents to be better prepared to help their children cope with their health care experiences. This could be done by Child Life Specialists informing parents of procedures they can be involved in, such as blood draws, medical imaging procedures, and IV placements, educating parents on how to advocate for supporting their child, and providing tools for the parents to use to help their children cope more effectively with procedures. This suggestion is given based on the author's observation of parents stepping back and watching when medical staff approach a patient to perform a procedure. A common feeling among patients and families is that medical staff are professionals with authority and are not to be interfered with. However, with proper education, parents can be empowered and can be better prepared to support their children when Child Life Specialists are not available to provide the support.

Additionally, Child Life could utilize a flier or brochure that outlines the types of services that can be provided by Child Life in order to better inform parents of the

services available and to encourage patients and parents to advocate for their needs through the volunteer program available at PCH. With a brochure, the Child Life Specialist can share the services offered by Child Life to the patients and families without increasing the amount of time spent with each patient and family. This is important to consider, given that the patient to Child Life Specialist ratio does not allow for thorough explanation of Child Life Services to each patient and family. Furthermore, the Child Life staff can better inform parents of the volunteer group that is available via the playroom programming at PCH to provide art, crafts, toys, and games to the patients through a brochure. The phone number to reach the volunteers could be provided on the brochure, giving patients and families more control over requesting and receiving desired activities.

In the category of services that promote coping, mothers largely indicated that the services provided by Child Life were beneficial. This is reassuring, especially considering that the services mentioned are skills that Child Life Specialists are taught to provide throughout their education and training and are the primary services offered by Child Life. Thus, it seems appropriate to state that improved Child Life Specialist to patient ratio would be beneficial so that these services that are valued by patients and families can be provided to a higher number of people. Mothers did report dissatisfaction regarding the quantity of Child Life Services offered or available to siblings. Once again, the issue of sibling support not being provided adequately or at all can be addressed by a lower Child Life Specialist to patient ratio as the Child Life Specialist would have the time to target more than one Child Life need per patient instead of only having the time to address the most pressing need, which is often related to the patient's health care

experience. When the Child Life Specialist is able to address the most pressing need and can then follow-up to assess other needs, siblings are more likely to be included in services. Increased awareness of the importance of sibling support, as well as the simple ways by which sibling support can be provided, for example sending home crafts with the parents, can also improve the support provided for the siblings.

The third category of suitability of services pointed to the need for more activities that are geared toward older school age and adolescent patients and siblings and for Child Life Specialists to ensure that the services they are providing are meaningful to the patients and families. At PCH, the types of resources available for the patients and families are largely based off of donations provided by members of the community. These donations are organized through a group of staff known as "Foundation." The need for more appropriate activities for older patients and siblings can be addressed by the Child Life staff coordinating with Foundation to request more late school age and adolescent craft and toy donations.

The issue of Child Life Specialists needing to be more accurate in their assessment of and interventions for patients and families may be at least partially resolved by increasing staff. It can be presumed that a lower patient to Child Life Specialist ratio will result in the Child Life Specialist being able to spend more quality time with the patients and families and thus be able to better assess and follow-up on interventions to know what is most supportive to each patient and family. Improving assessment skills through education opportunities can also address this issue. Education is currently offered in a variety of settings at PCH, including learning forums, clinical supervision meetings, and department trainings. Knowing that families sometimes need

an intervention that is different from what is provided is helpful for providing education opportunities for the Child Life staff that will improve outcomes for patients and families. Thus, education about how to assess needs would be beneficial.

It would also be beneficial to discuss ways to better understand patient and family needs through communication. It is suggested that when a Child Life Specialist meets a family and makes an assessment about how the patient and family are coping, the Child Life Specialist not only offers and discusses options for interventions with the family, but also follows-up with the patient and family on how effective the intervention was. With an understanding of what the intervention is and how it can support the patient and family, patients and families may, and sometimes do, decline specific services. Additionally, patients and families sometimes will agree to an intervention, however, upon participating in the intervention, they may decide that it did not meet their needs. Open communication between the patient, family, and Child Life Specialist about the purpose of specific interventions and follow-up about the effectiveness of the interventions chosen can improve the quality and effectiveness of Child Life Services as perceived by mothers. It would then be beneficial, when a Child Life Specialist knows patient's and family's preferences, for the Child Life Specialist to include the preferences in the patient's chart notes in order to also improve communication between Child Life Specialists and other members of the health care team to improve the overall healthcare experience for patients and families.

CONCLUSION

The strengths of this study included the solid organ transplant population being studied in relation to patient and family outcomes, as well as Child Life Services being evaluated by mothers, both of which have not been previously studied. Additionally, this study included both parent and sibling report. However, the sibling report did not produce any statistically significant findings. There were also limitations to the present study. The participants came from a highly homogenous group of patients and families. The majority of the families were White, middle-class, married, and of the same religious affiliation. Additionally, the number of participants created low power to detect significant results with the quantitative analyses. The present study sought to understand the relationships between the impact of the illness on the family, sibling functioning, and participation in and satisfaction with Child Life Services. It also sought to provide valuable information regarding the role of Child Life Services in providing developmentally appropriate interventions that lead to decreased stress and increased coping to children and their families. Implications of the present study included a need for more research regarding the effects of solid organ transplant on patient and family well-being. Furthermore, additional Child Life research needs to be conducted in order to further understand the role of Child Life Services as a meaningful part of the health care team. It is also implied from the data presented that Child Life to patient ratios need to be addressed in order to best meet the needs of each patient and family.

APPENDIX A

TRANSPLANT CARE QUESTIONAIRE

Please answer the following questions about your child that has received a heart, kidney, or liver transplant as accurately as possible.

1. Currently, how old is your child that received a heart, kidney, or liver transplant?

   _____

2. What type of transplant did your child receive?
   a. Heart
   b. Kidney
   c. Liver

3. What is the month and year of your child's transplant(s)?
   a. Month: _____
   b. Year: _____

4. Currently, approximately how many minutes or hours **per day** do you spend helping your child with his or her medical needs that are directly related to the heart, kidney, or liver transplant? This can include reminding your child to take medication, supporting your child while he or she takes medication, helping your child with line care, taking your child to appointments, or staying with your child at the hospital.

   _____

5. Currently, approximately how many minutes or hours **per day** does your child spend maintaining his or her medical needs independently (without your help)?

   _____

6. Currently, does your child resist taking his or her anti-rejection medications **at least once a week**?
   a. Yes

b. No
    i. If yes, how often do you struggle with your child to get him or her to take the anti-rejection medications?

    _____

    ii. If yes, why do you believe your child resists taking the anti-rejection medications?

    _____

APPENDIX B

CHILD LIFE SERVICES SURVYEY

Primary Children's Hospital (PCH) and the University of Utah employ Child Life Specialists as part of their health care team. The role of a Child Life Specialist is to provide developmental support in a healthcare setting. The support provided includes the following services:

- Emotional support to patients and their families
- Preparation of patients and family members for health care experiences such as admission to the hospital and medical and surgical procedures
- Assessment of children's development and behavior needs
- Opportunities for normal play activities and therapeutic medical play experiences
- Teaching of distraction, diversion, and relaxation techniques to help with coping and stress throughout healthcare experiences
- Distraction, diversion, and relaxation support during intrusive procedures
- Sibling support
- Grief support

The purpose of this survey is to ask you about your experience with Child Life Services at Primary Children's Hospital and/or the University of Utah. Unless specified, the reference to receipt of Child Life Services includes you as the parent, your child who received a solid organ transplant, and/or the sibling participating in the study. Please complete this survey as honestly and accurately as possible. If an open-ended question does not apply to you, please write that it is not applicable or N/A.

1. Are you familiar with the Child Life Services available at PCH and University Hospital?
    a. Yes
    b. No

*If you answered no, you are now done with this survey. Thank you for your response!

2. If you are familiar the Child Life Services available at PCH and University Hospital, did you, your child, and/or the sibling participate in Child Life Services?
    a. Yes
    b. No

*If you answered no, please skip to question 34.

3. If yes, how often do you feel that you and your family received Child Life Services during your visits at PCH or University Hospital for **Outpatient** visits?
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Always

4. How satisfied are you with the services received during **outpatient** visits?
    a. Very Unhappy
    b. Somewhat Unhappy
    c. Neither Happy or Unhappy
    d. Somewhat Happy
    e. Very Happy
    f. Not Applicable

5. How satisfied are you with the **availability** of Child Life Services during **outpatient** visits?
    a. Very Dissatisfied
    b. Dissatisfied
    c. Neither Dissatisfied nor Satisfied
    d. Satisfied
    e. Very Satisfied

6. Please select the kind of services you/your child/the sibling received from Child Life during **outpatient** visits. Select all that apply.
    a. Emotional support (listening, validating feelings, etc.)
    b. Preparation for procedures
    c. Support during procedures
    d. Medical play
    e. Other play opportunities (arts/crafts, games—not medical play)
    f. Sibling support (teaching sibling about brother or sisters medical needs, answering questions, listening to siblings' concerns, etc.)
    g. Other
    _____
    h. Not Applicable

7. Please explain what aspects of the Child Life Services were helpful during **outpatient** visits. _____
_____
_____
_____
_____

8. Please explain what aspects of Child Life Services were NOT helpful during **outpatient** visits. _____
_____
_____
_____
_____

9. Please write anything else you feel is important about your experience with Child Life Services during your **outpatient** visits. _____
_____
_____
_____
_____
_____

10. What do you think could be done differently to improve Child Life Services for you/your child/the sibling during **outpatient** visits? If your suggestion is specific for parents, patients, or siblings, please specify. _____
_____
_____
_____
_____
_____

11. If you are familiar with Child Life Services, how often do you feel that you and your family received Child Life Services during your **inpatient** stays at PCH or University Hospital?
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Always

12. How satisfied are you with the Child Life services received during **inpatient** stays?
    a. Very Unhappy
    b. Somewhat Unhappy
    c. Neither Happy or Unhappy
    d. Somewhat Happy

e. Very Happy
f. Not Applicable

13. How satisfied are you with the **availability** of Child Life Services during **inpatient** stays?
    a. Very Dissatisfied
    b. Dissatisfied
    c. Neither Dissatisfied nor Satisfied
    d. Satisfied
    e. Very Satisfied

14. Please select the kind of services you/your child/the sibling received from Child Life during **inpatient** stays. Select all that apply.
    a. Emotional support (listening, validating feelings, etc.)
    b. Preparation for procedures
    c. Support during procedures
    d. Medical play
    e. Other play opportunities (arts/crafts, games—not medical play)
    f. Sibling support (teaching sibling about brother or sisters medical needs, answering questions, listening to siblings' concerns, etc.)
    g. Other _____
    h. Not Applicable

15. Please explain what aspects of Child Life Services were helpful during **inpatient** stays. _____
    _____
_____
_____
_____
_____

16. Please explain what aspects of Child Life Services were NOT helpful during **inpatient** stays. _____
    _____
_____
_____
_____
_____

17. Please write anything else you feel is important about your experience with Child Life Services during your **inpatient** stays. _____
    _____
_____
_____

_____
_____

18. What do you think could be done differently to improve Child Life Services for you/your child/the sibling during **inpatient** stays? If your suggestion is specific for parents, patients, or the sibling, please specify. _____
_____
_____
_____
_____
_____

19. Overall, how satisfied are you with the Child Life Services you received (both inpatient and outpatient) throughout your child's transplant experience?
    a. Very Unsatisfied
    b. Unsatisfied
    c. Neither Unsatisfied or Satisfied
    d. Satisfied
    e. Very Satisfied

20. Overall, what Child Life services or experiences were **most** helpful to **you**, as a parent, throughout the transplant experience? (Your child and the sibling will be asked about in the following questions.) _____
_____
_____
_____
_____
_____

21. Overall, what Child Life services or experiences were **most** helpful for **your child** throughout the transplant experience? _____
_____
_____
_____
_____
_____

22. Overall, what Child Life services or experiences were **most** helpful for **the sibling** throughout the transplant experience? If the sibling did not participate in Child Life services, please explain why. _____
_____
_____
_____
_____
_____

23. Overall, what Child Life services or experiences were **least** helpful to you, as the **parent**, throughout the transplant experience? (Your child and the sibling will be asked about in the following questions.) _____
_____
_____
_____
_____
_____

24. Overall, what Child Life services or experiences were **least** helpful for **your child** throughout the transplant experience? _____
_____
_____
_____
_____
_____

25. Overall, what Child Life services or experiences were **least** helpful for **the sibling** throughout the transplant experience? _____
_____
_____
_____
_____
_____

26. Overall, what do you think could be done differently to improve Child Life Services for you/your child/the sibling? If your response is specific to parents, the patients, or the siblings, please specify. _____
_____
_____
_____
_____
_____

27. At PCH, Child Life offers SIBS day (Super Important Brother's and Sister's) for the brothers and sisters of children with a chronic illness. Are you familiar with the opportunity for the sibling to participate in SIBS day?
    a. Yes
    b. No

28. If yes, did the sibling participate in SIBS day?
    a. Yes
    b. No
    c.

29. If you are familiar with SIBS day, but the sibling did not participate, why did the sibling NOT participate?

a. We had schedule conflicts
b. We live too far away from the hospital
c. We were not informed of SIBS DAY soon enough
d. The sibling was not interested in SIBS day
e. SIBS day is too expensive
f. Other_____

*If the sibling did NOT participate in SIBS day and you answered all of the previous questions, you are now done with this survey. Thank you for your response!

30. If the sibling participated in SIBS day, how many times did the sibling participate?
    a. Once
    b. Twice
    c. Three or more times

31. What aspect of SIBS day was **most** helpful for **the sibling**? _____
_____
_____
_____
_____
_____

32. What aspect of SIBS day was **least** helpful for **the sibling**? _____
_____
_____
_____
_____
_____

33. What do you think could be done differently to improve SIBS day for siblings of children with chronic illness? _____
_____
_____
_____
_____
_____

*If you answered all previous questions, you are now done with this survey. Thank you for your response!

34. If you did not participate in Child Life Services, but are familiar with the services at PCH and University Hospital, why did you not participate?
    a. Not interested in Child Life Services/Don't think it is a worthwhile service
    b. Took too much time

c. Live too far away from the hospital to consider services
d. Other _____

REFERENCES

Achenbach, T. (2011). Brief problem monitor-parent form for ages 6-18. Achenbach System of Empirically Based Assessment.

Annunziato, R. A., Jerson, B., Seidel, J. & Glenwick, D. S. (2012). The psychosocial challenges of solid organ transplant recipients during childhood. *Pediatric Transplantation*, *16*(7), 803–811.

Bender, H. A., Auciello, D., Morrison, C. E., MacAllister, W. S., & Zaroff, C. M. (2008). Comparing the convergent validity and clinical utility of the Behavior Assessment System for Children-Parent Rating Scales and Child Behavior Checklist in children with epilepsy. *Epilepsy & Behavior, 13*(1), 237-242.

Besier, T., Hölling, H., Schlack, R., West, C., & Goldbeck, L. (2010). Impact of a family-oriented rehabilitation programme on behavioural and emotional problems in healthy siblings of chronically ill children. *Child: Care, Health and Development. 36*(5), 686-695.

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46*(6), 722-730.

Chernoff, R. G., Ireys, H. T., Devet, K. A., & Kim, Y. J. (2002). A randomized, controlled trial of a community-based support program for families of children with chronic illness: Pediatric outcomes. *Pediatric Adolescent Medicine*, *156*, 533-539.

Gross, D., Fogg, L., Young, M., Ridge, A., Cowell, J. M., Richardson, R., & Sivan, A. (2006). The equivalence of the Child Behavior Checklist/1 1/2-5 across parent race/ethnicity, income level, and language. *Psychological Assessment, 18*(3), 313-323.

Guite, J., Lobato, D., Kao, B., & Plante, W. (2004). Discordance between sibling and parent reports of the impact of chronic illness and disability on siblings. *Children's Health Care, 33*(1), 77-92.

Havermans, T., Wuytack, L., Deboel, J., Tijtgat, A., Malfroot, A., De Boeck, C., & Proesmans, M. (2011). Siblings of children with cystic fibrosis: Quality of life and the impact of illness. *Child: Care, Health and Development, 37*(2), 252-260.

Kao, B., Plante, W., & Lobato, D. (2009). The use of the Impact on Sibling Scale with families of children with chronic illness and developmental disability. *Child: Care, Health and Development, 35*(4), 505-509.

Leech, N. L., & Onwuegbuzie, A. J. (2008). Qualitative data analysis: A compendium of techniques and a framework for selection for school psychology research and beyond. *School Psychology Quarterly, 23*(4), 587-604

Lobato, D. J., & Kao, B. T. (2005). Brief report: Family-based group intervention for young siblings of children with chronic illness and developmental disability. *Journal of Pediatric Psychology, 30*(8), 678-682.

Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology, 27*(8), 699-710.

Stewart, S. M., Kennard, B. D., DeBolt, A., & Petrik, K. (1993). Adaptation of siblings of children awaiting liver transplantation. *Children's Health Care, 22*(3), 205-215.

Thompson, R.H. (2009). *The handbook of child life: A guide for pediatric psychsocial care*. Springfield, IL: Charles C Thomas, Publisher, LTD.

Waite-Jones, J. M., & Madill, A. (2008). Amplified ambivalence: Having a sibling with juvenile idiopathic arthritis. *Psychology & Health, 23*(4), 477-492.

Williams, P. D., Ridder, E. L., Setter, R. K., Liebergen, A., Curry, H., Piamjariyakul, U., & Williams, A. R. (2009). Pediatric chronic illness (cancer, cystic fibrosis) effects on well siblings: Parents' voices. *Issues in Comprehensive Pediatric Nursing, 32*(2), 94-113.

Williams, P. D., Williams, A. R., Graff, C. J., Hanson, S., Stanton, A., Hafeman, C., . . . Sanders, S. (2002). Interrelationships among variables affecting well siblings and mothers in families of children with a chronic illness or disability. *Journal of Behavioral Medicine, 25*(5), 411-424.

Wilson, J., Palm, S., & Skinner, L. (2006) *Guidelines for the development of child life programs in health care settings* (4th ed). Rockville, MD: Child Life Council.